



February 19, 2015

**Judy Brown, Associate Professor in Residence, UCONN**  
*in support of*  
**SB 857- AN ACT CONCERNING LICENSURE FOR GENETIC COUNSELORS**  
**February 20, 2015**

Dear State Representatives and Senators,

I am writing to ask you to support the licensing of genetic counselors in the state of Connecticut (SB 857). Over one third of genetic counselors in the U.S. are licensed and many other states are working towards this effort. There exists a need for interdisciplinary Allied Health researchers and practitioners who can translate the explosion of research about genetic and genomic links to disease risk into tailored health promotion approaches that maximize health and improve quality of life. I have a doctorate degree in Genetics and Genomics with a master's degree in Allied Health. I am also a certified clinical laboratory specialist in cytogenetics and molecular genetics, an active researcher in cytogenomics, and have been teaching, training and collaborating with counselors, students and researchers in the accredited Diagnostic Genetics, Dietetics and Medical Lab Programs, and those in Pathology, Molecular Cell, and Health Promotion. As Director of the Professional Science Masters Degree in Health Care Genetics, together with key faculty in Storrs and Farmington, I provide relevant didactic and experiential components to further meet the growing demand for professionals with interdisciplinary competency in genetics, counseling, diagnostics, ethics, and regulatory issues.

Many of the students who complete the Diagnostic Genetic Sciences Program have gone on to be trained in genetic counseling and earn their professional certification. As a clinical laboratory technologist, there is much interaction with the genetic counselors with respect to test ordering, patient evaluation, and weekly case-studies. As a member of the American Society Human Genetics (ASHG) and an active member on the CT Dept of Public Health Expert Genomics Advisory Panel since 2010, I am well aware of not only the shortage of trained genetic counselors, but also that genetic counselors are professionals whose training includes a Master's degree and mandatory continuing education. Genetic counselors have expertise in genetics and genetic counseling and function as an essential member of the health care team.

Genetic counselors also train other health care providers and students, and many in CT have collaborated with me for the education of UCONN undergraduate and graduate students. Given the recent explosion of personalized genomic medicine, all of our graduates are expected to be able to understand that health-related genetic information can have important social and psychological implications for individuals and families, identify resources available to assist those seeking genetic information or services, and discuss interdisciplinary issues related to the impact of genomics on health care. Three students, myself and Robin Schwartz (certified genetic counselor) put together a screen play that was enacted on November 19, 2014 titled: It's Not that Simple and It's So Complicated. Student actors shed light on the complexity of emotions, reactions, and implications from the informed consent process through to disclosure of next generation genetic testing results. Three certified genetic counselors from UCONN Health (Robin Schwartz, Sharon Lavigne, and Brittany Gancarz) helped narrate and lead discussion, and following a dinner, met with students to talk about genetic counseling as a career. Students reflected on the complexity of the scientific, ethical, psychological, societal, legal, and policy issues of genetic and genomic testing and research. This was a unique learning experience with

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diverse participants, an excellent modality to involve many professionals and programs in learning about NEXT GEN testing.

Genetic counselors have the ability to explain, accurately and in easy-to-understand terms, difficult and constantly evolving genetic information to patients; evaluate a complex family history; and, evaluate the need for genetic testing. With the rapid advances in genetic technology, genetic testing and counseling services are quickly moving to the forefront of biosciences. Counselors are responsible for explaining complicated testing and technologies, are required to explain these complicated tests and technologies in an understandable manner, and must convey both the risks and usefulness of these tests. Genetics is a rapidly changing field, with new discoveries on an almost daily basis. Unlike researchers, genetic counselors must remain current, not only for professionalism, but because patients are watching the news stories. Furthermore, counselors must be able to provide information and supportive care *tailored* to each patient and/or family. With this in mind, licensure is needed in order to ensure that the quality of these professionals remains high and that the public is afforded the best level of care.

Incorporating genetic counselors into the testing process has been shown to lead to cost-efficient risk identification and more appropriate genetic testing, with significant savings in healthcare spending for patients with cancer, neurological disorders, and cardiac disorders. Licensure can protect the patients and CT residents from unqualified providers, and unregulated practices. There has been increase in “direct to consumer testing” for complete genome testing to tailored nutritional plans based on genetic makeup, with many tests and companies, not regulated by the FDA. The public wants to know, and to know quickly. However, given the complicated reports, and especially given that most genetic reports have “variants of unknown significance” or “risks” rather than diagnoses, genetic counselors are our State’s safety mechanism. The State can prevent harm by ensuring that providers who represent themselves as genetic counselors have the appropriate training, licensure and continuing education. A recent report from ARUP Laboratories, a national pathology lab affiliated with the University of Utah, found that over an 11-month period in 2010, clinicians ordered the wrong genetic test nearly a third of the time. A 2012 study in The Cancer Journal reviewed dozens of cases in which doctors without specialized training made similar mistakes: ordering wrong or unneeded genetic tests, misinterpreting the results of correct tests, or failing to refer a patient to a genetic counselor even when there were key red flags, like a strong family history for a disease. **Licensure is needed in order to ensure that the quality of these professionals remains high and that the public is afforded the best level of care.** Thank you for your time, interest and caring. Please do not hesitate to contact me if I can provide any additional information in support of this licensure act.

Respectfully,



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